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## Review Article

## Maternity care experiences of women with physical disabilities: A systematic review



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## ABSTRACT

**Objective:** Fifteen percent of the world's population has some form of disability, the most common form being a physical disability. Ten percent of women with disabilities are of childbearing age; however, because women with disabilities are often deemed less likely to have children, accessibility to maternity care is limited. Women with disabilities experience problems during pregnancy and childbirth due to physical barriers and barriers to information, problems with communication and the attitude of providers. A recent World Health Organization statement calls for more action, dialogue, research and advocacy on disrespectful treatment during childbirth. To give substance to this, an overview of the experiences of women with a physical disability is essential. Therefore, the aim of this systematic review is to identify and provide an overview of reported maternity care experiences of women with physical disabilities, including sensory disabilities.

**Design:** This systematic review was conducted using a meta-aggregation approach for synthesis and the steps of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement. The search strategy focused on qualitative studies in the databases PubMed, Embase and CINAHL. The Critical Appraisal Skills Programme checklist was used to evaluate methodological quality, and a best-evidence synthesis was performed.

**Findings:** Of the 4,486 studies screened, ten were included. The methodological quality of the studies ranged from high to moderate. The results indicated that women experience barriers related to accessibility of facilities, adapted equipment, lack of knowledge, and healthcare providers' dismissals of their concerns and unwillingness to assist. In contrast, support has a positive influence on women's experiences.

**Key conclusions and implications for practice:** There is evidence that women with physical disabilities continue to encounter barriers in accessing maternity care related to inaccessible care settings, lack of knowledge and the attitude of healthcare providers. Healthcare providers should be trained to be aware of women's special needs and to improve clinical practice.

## Introduction

Worldwide, more than one billion people, or fifteen percent of the world's population, have some type of disability (World Health Organization, 2011a; World Health Organization and World Bank, 2011). Disabled people belong to the largest minority group (World Health Organization, 2018). According to the World Health Organization (WHO), disabilities are 'an umbrella term, covering impairments, activity limitations and participation restrictions'

(World Health Organization, 2011b). The main categories of disabilities are intellectual, cognitive, neurological, psychiatric, physical and sensory. Of these, physical disabilities are the most common (Government of Western Australia Department of Communities Disability Services, 2015). A physical disability can be defined as 'a long-term loss or impairment of a person's body function, resulting in limited mobility, endurance, dexterity or physical function' (GPII DeveloperSpace, 2019). Physical disabilities are known as sensory disabilities if they affect sight, speech, hearing or language (DomusVi, 2019).

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Ten percent of women with disabilities are of childbearing age; however, they are often assumed to not be sexually active and less likely to have children (Ahumuza et al., 2014; World Health Organization and World Bank, 2011). This perception has led to limited access by women with disabilities to sexual and reproductive health services (Ahumuza et al., 2014; Morrison et al., 2014). While the precise prevalence of pregnancy among women with physical disabilities is unknown, it is not insignificant, and is likely to increase (Iezzoni et al., 2013). With increased community involvement, medical advances, and the recognition of the reproductive rights of people with disabilities, women with disabilities have increased opportunities for childbirth (“Americans with disabilities act of 1990, as amended,” 2008; Hendriks, 2007).

However, women with disabilities experience problems during pregnancy and childbirth due to physical barriers, lack of specialised services, problems with the healthcare system and barriers to information, problems with communication and the attitude of providers (Scheer et al., 2008; Schopp et al., 2002). The attitudes and behaviours of maternity care providers may directly affect the well-being of patients and the relationship between patients and providers (World Health Organization, 2005). Maternity care can be defined as ‘the constellation of health services provided by a physician, nurse, midwife, hospital or birthing centre to a pregnant woman during pregnancy (prenatal care), delivery, and after delivery (postnatal care)’ (Segen’s Medical Dictionary, 2011). Lack of respectful care from these providers may lead to dissatisfaction with the healthcare system and decrease the likelihood of seeking maternity care (World Health Organization, 2005).

A recent WHO statement calls for more action, dialogue, research and advocacy on disrespectful and abusive treatment during childbirth in facilities around the world and has launched a program to promote reproductive health among disabled people (World Health Organization, 2015, 2009). In 2015, Tarasoff published a literature review on the perinatal care experiences of women with physical disabilities (Tarasoff, 2015). According to this review, women with physical disabilities experience attitudinal barriers and lack of knowledge on disabilities from healthcare providers. Furthermore, physical barriers such as inaccessible examination tables, delivery rooms and beds are reported (Tarasoff, 2015). However, there has been no systematic review of qualitative research concerning the maternity care experiences of women with physical disabilities, including sensory disabilities such as visual impairment.

To improve care experiences, which can consequently improve maternal and neonatal outcomes, it is necessary to remove barriers in maternity care for pregnant women with disabilities (Clements et al., 2016; Tarasoff, 2015). It is therefore recommended to perform a systematic review regarding the experiences of women with disabilities in maternity care and what these women encounter to improve their experiences. This review describes commonly reported experiences to address these barriers in clinical practice. The synthesised findings can be used to inform policy or healthcare practices to improve the quality of maternity care. The aim of this review is to identify and provide an overview of the reported experiences of women with physical disabilities, including sensory disabilities, regarding maternity care.

## Methods

This systematic review was conducted using the meta-aggregation approach for qualitative research synthesis (Lockwood et al., 2015) and the steps of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher et al., 2009a) for reporting systematic reviews.

### Search strategy

A systematic literature search was conducted on the 13<sup>th</sup> of February 2019 without limit features in the following databases: PubMed, Embase and CINAHL. Reference lists of included studies were searched by

hand, and articles citing those studies were searched in Scopus to identify additional relevant studies. A final search was performed October, 16, 2020.

The search terms contained subheadings (e.g. MeSH) and free-text words. Two researchers (MHG and MV) agreed on a final search string involving multiple related terms and synonyms to identify relevant studies, such as ‘Obstetrics’, ‘Disabled Persons’ and ‘Experience’ (Appendix I). To ensure a comprehensive search, there were no restrictions on the country of research or publishing year.

### Selection criteria

This systematic review focused on the domain ‘women with physical disabilities’, determinant ‘maternity care’ and outcome ‘experience’. Since the underlying causes are investigated, qualitative studies and qualitative data extracted from mixed methods studies that addressed the experiences of women with physical disabilities regarding maternity care were considered relevant. For practical reasons, only articles in English and Dutch were included.

This systematic review was limited to articles concerning physical or sensory disabilities, as people with intellectual impairments appear to be more disadvantaged in many settings (Roulstone and Barnes, 2005). Studies on domestic abuse, and studies on the experiences of physically disabled women with pregnancy and birth, in which the purpose was not to investigate maternity care, were also excluded. Additionally, studies including other people such as healthcare providers and family members were excluded.

The Rayyan web tool was used for study selection (Ouzzani et al., 2016). After duplicate resolution, all titles and abstracts were screened by both researchers (MHG and MV) for eligibility against the criteria for inclusion and exclusion. Next, the full text was screened by MHG. Studies of which it was unclear whether they met the criteria for inclusion or exclusion were independently screened by the second researcher (MV) and discussed until consensus was reached. Other members of the research group were consulted in case of any remaining doubts. Studies that addressed the maternity care experiences of women with physical disabilities and were available in full text were reviewed in detail.

### Methodological quality

The Critical Appraisal Skills Programme (CASP) qualitative checklist (Critical Appraisal Skills Programme, 2018) was used to evaluate the methodological quality of the studies. The checklist contains ten questions that can be answered with ‘yes’, ‘can’t tell’ or ‘no’. A number of hints are provided after each question. The research team decided to rate ‘yes’ with one point, ‘can’t tell’ with half a point and ‘no’ with zero points to be able to link a quality score. Studies with a quality score of 0–4 points were classified as low quality studies, with 5–7 points as moderate quality and with 8–10 points as high quality. Both researchers (MHG and MV) independently evaluated the quality score of each study using the CASP checklist. Differences in ratings were discussed with the research team until consensus was reached (MHG, MV, AH).

### Data extraction

Data extraction was performed in the following phases according to meta-aggregation (Lockwood et al., 2015): 1) General details of the studies were extracted, including the country of research, methodology, sample size, disability type, analytical approach, key themes and conclusions; 2) The verbatim extract of the findings from the author’s analytical interpretation of data relevant to the research question was imported into Microsoft Excel. The findings were identified by repeated reading and accompanied by an illustration from the same study, such as a direct quotation or other data supporting the finding; 3) Plausibility levels were assigned based on evaluation by two researchers (MHG and MV). The plausibility levels are as follows (Lockwood et al., 2015):

- *Unequivocal*: findings accompanied by an illustration that are beyond reasonable doubt and therefore not open to challenge;
- *Equivocal*: findings accompanied by an illustration lacking clear association with it and therefore open to challenge;
- *Unsupported*: findings not supported by the data.

Ranked unequivocal and equivocal findings share equal recognition in the synthesis, while unsupported findings do not appear. The reasons for level allocation were documented.

### Synthesis

A three-phase approach to thematic analysis was adopted on the basis of the meta-aggregation method (Lockwood et al., 2015): 1) As described in the section on data extraction, the extraction of all findings from all included studies was accompanied by illustrations and assigned a plausibility level; 2) Categories were developed for findings, with at least two findings from different studies per category. Categorisation involved repeated, detailed analysis of the findings. Findings that were similar in meaning were grouped together into one category. Each category was accompanied by a combination of a brief description of the key concept and an explanatory statement; 3) Synthesised findings were developed as an overarching description of at least two categories (Lockwood et al., 2015). The categories and synthesised findings were discussed until consensus was reached.

A best-evidence synthesis was performed to summarise all findings, taking into account the methodological quality, number of studies and

consistency of the findings. *Strong evidence* was defined as consistent findings in multiple high-quality studies. *Moderate evidence* was defined as consistent findings in one high-quality study and at least one low-quality study. *Insufficient evidence* was defined as only one available study or inconsistent findings in multiple studies (Proper et al., 2011).

### Results

After duplicate resolution, the database search resulted in 4,479 potentially relevant studies. A manual search in Scopus and reference lists resulted in seven additional studies. A total of 4,486 studies were screened by title and abstract. After discussing the studies of which it was unclear whether they could be included, 33 studies remained. These studies were screened for eligibility by reading full text.

Due to the specific context of domestic abuse, four articles were excluded, five due to the inclusion of people with intellectual disabilities and two due to the inclusion of other people. Eleven articles focused on pregnancy or childbirth and not specifically on maternity care. One article was excluded due to Norwegian language.

Studies of which it was unclear whether they could be included were discussed with a second researcher (MV), resulting in nine relevant qualitative studies (Bertschy et al., 2015; Frederick, 2015; Ganle et al., 2016; Lipson and Rogers, 2000; Mazurkiewicz et al., 2018; Mitra et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2017; Tarasoff, 2017) and one mixed methods study from which only qualitative data was used (Smeltzer et al., 2016). Figure 1 provides a flow diagram of the

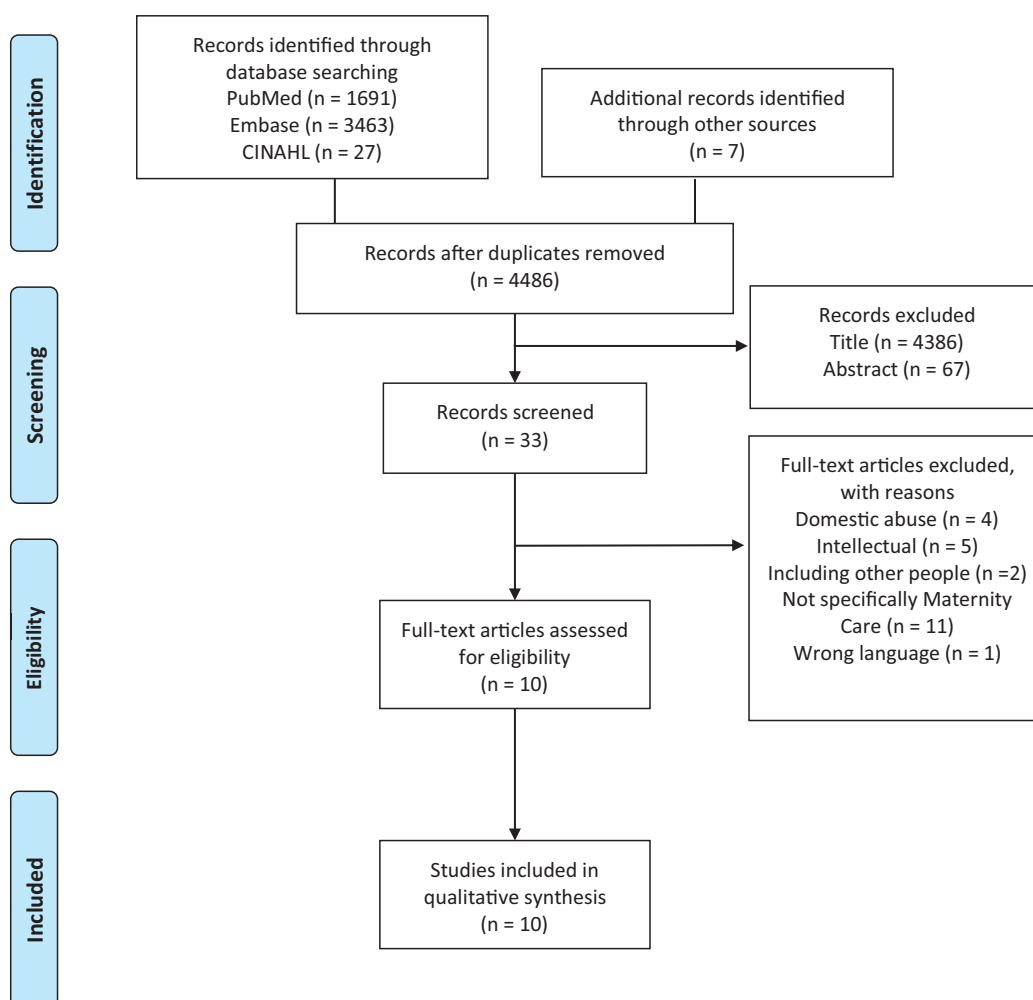


Fig. 1. PRISMA flow diagram of study selection.

**Table 1**  
Study characteristics.

Article	Methodology	Sample	Disability	Analytic approach	CASP Quality
Bertschy et al., 2015 Switzerland	5 Individual interviews - 45-60 minutes 4 Focus groups - 120-180 minutes Semi-structured interview guide.	n = 17	Physical	Qualitative Content Analysis based on Anderson's behavioral model.	10
Nguyen et al., 2020 Vietnam	56 interviews - 29 first interviews - 27 follow-up interviews Physical access audit - 14 facilities Semi-structured interview guide and access audit checklist	n = 29	Physical	Thematic analysis guided by the Braun and Clarke approach. NVivo was used.	9.5
Mazurkiewicz et al., 2018 Poland	Individual interviews - Average 60 minutes Semi-structured interview guide.	n = 16	Sensory - Visual	Interpretative Phenomenological Analysis approach	9
Mitra et al., 2016 USA	Individual interviews  - By phone. Semi-structured interview guide.	n = 25	Physical	Kurasaki's method used for reliability and consistence of coding. Atlas.ti was used.	9
Smeltzer et al., 2017 USA	Individual interviews - By phone - Average 120 minutes Semi-structured, open-ended interview protocol.	n = 22	Physical	Conventional content analysis facilitated by NVivo.	9
Tarasoff, 2017 Canada	In-depth interviews - 10 in person - 3 by phone - 54-135 minutes Follow-up interviews - 10 by phone Semi-structured interview guide.	n = 13	Physical Sensory - Visual (n=1)	Informed by a grounded theory approach.	9
Ganle et al., 2016 Ghana	In-depth interviews - 60-90 minutes Semi-structured interview guide.	n = 72	Physical (n=47) Sensory - Visual (n=7) - Speech (n=6) - Hearing (n=12)	Attride-Stirling's thematic network analysis framework.	8.5
Smeltzer et al., 2016 USA	Individual interviews - By phone. Semi-structured interview guide	n = 25	Physical	Traditional content analysis. Atlas.ti was used.	8.5
Lipson and Rogers, 2000 USA	Individual interviews - 60-120 minutes Interview schedule.	n = 12	Physical	Not reported	6.5
Frederick, 2015 USA	14 Individual interviews - 2 in person - 12 by phone 3 Focus groups. A series of questions	n = 26	Sensory - Visual	Not reported	5.5

full screening process (Moher et al., 2009b). Appendix I provides an overview of the databases in which the articles appeared.

### Study characteristics

The characteristics of the included studies are presented in Table 1. The studies were conducted in Switzerland (Bertschy et al., 2015), Vietnam (Nguyen et al., 2020), Ghana (Ganle et al., 2016), Poland (Mazurkiewicz et al., 2018), Canada (Tarasoff, 2017) and the United States (Frederick, 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Smeltzer et al., 2017, 2016), and were published between 2000 and 2020. Seven studies used individual interviews (Ganle et al., 2016; Lipson and Rogers, 2000; Mazurkiewicz et al., 2018; Mitra et al., 2016; Smeltzer et al., 2017, 2016; Tarasoff, 2017), two studies combined individual interviews with focus groups (Bertschy et al., 2015; Frederick, 2015) and one study combined interviews with physical access audits (Nguyen et al., 2020). Five studies conducted interviews in person (Bertschy et al., 2015; Ganle et al., 2016; Lipson and Rogers, 2000; Mazurkiewicz et al., 2018; Nguyen et al., 2020), three studies conducted interviews by phone (Mitra et al., 2016; Smeltzer et al., 2017, 2016) and two studies conducted interviews both in person and by phone (Frederick, 2015; Tarasoff, 2017). A

total of seven focus groups were executed (Bertschy et al., 2015; Frederick, 2015). Eight studies used a semi-structured interview guide (Bertschy et al., 2015; Ganle et al., 2016; Mazurkiewicz et al., 2018; Mitra et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2017, 2016; Tarasoff, 2017), one used an interview schedule (Lipson and Rogers, 2000) and one used a series of questions (Frederick, 2015).

A total of 257 women with physical and/or sensory disabilities were included. One woman had a combination of a physical and sensory disability in the form of blindness. A total of 189 women had a physical disability, 49 had visual impairment, six had a speech impairment and 12 had a hearing impairment.

### Methodological quality

The methodological quality (CASP quality score) ranged from 5.5 to 10, with an average of 8.5 (Table 2). Eight articles were classified as high-quality studies (Bertschy et al., 2015; Ganle et al., 2016; Mazurkiewicz et al., 2018; Mitra et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2017, 2016; Tarasoff, 2017), while two studies were classified as moderate-quality studies (Frederick, 2015; Lipson and Rogers, 2000).

**Table 2**  
CASP checklist and CASP quality score.

	Bertschy et al., 2015	Nguyen et al., 2020	Mazurkiewicz et al., 2018	Mitra et al., 2016	Smeltzer et al., 2017	Tarasoff, 2017	Ganle et al., 2016	Smeltzer et al., 2016	Lipson and Rogers, 2000	Frederick, 2015
<b>Section A: Are the results valid?</b>										
1.	Was there a clear statement of the aim of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓
2.	Is qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓
3.	Was the research design appropriate to address the aims of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓
4.	Was the recruitment strategy appropriate to the aims of the research?	✓	✓	✓	✓	✓	✓	✓	—	✓
5.	Was data collected in a way that addressed the research issue?	✓	✓	✓	✓	✓	✓	✓	✓	?
6.	Has the relationship between researcher and participants been adequately considered?	✓	?	—	?	—	—	—	✓	—
<b>Section B: What are the results?</b>										
7.	Have ethical issues been taken into consideration?	✓	✓	✓	?	✓	✓	?	✓	—
8.	Was the data analysis sufficiently rigorous?	✓	✓	✓	✓	✓	✓	✓	✓	—
9.	Is there a clear statement of findings?	✓	✓	✓	✓	✓	✓	?	?	—
<b>Section C: Will the results help locally?</b>										
10.	How valuable is the research?	✓	✓	✓	✓	✓	✓	✓	—	✓
<b>CASP Quality Score (maximum 10 points)</b>		10	9.5	9	9	9	8.5	8.5	6.5	5.5
		✓	?	Can't Tell (0.5 points)	—	No (0 points)				

*Results of individual studies*

Although all studies reported the experience of physically disabled women with maternity care, the studies used different formats to display the categories and themes. Table 3 provides an overview of the key themes and results of the individual studies. The study by Frederick did not describe key themes or categories, but described how women with visual impairment experienced discrimination by healthcare providers during postnatal care (Frederick, 2015).

Bertschy et al. focused on women with spinal cord injury (SCI) (Bertschy et al., 2015). The main categories were deduced from An-

derson's behavioural model of health service utilisation and are as follows (Andersen, 1995): 1) Women's perceived health needs, and 2) The health services used. Sub-categories were developed by analysing the data.

Nguyen et al. included women with congenital or acquired physical disabilities caused by different factors, such as cerebral palsy (CP), polio or a traffic accident (Nguyen et al., 2020). Thematic analysis resulted in six themes. Findings from the physical access audits were consistent with the reported experiences of women with physical disabilities.

Mazurkiewicz et al. included women with visual impairment (Mazurkiewicz et al., 2018). The women were asked to freely voice



their opinions on five major themes that were pre-selected by the researchers. The Interpretative Phenomenological Analysis approach (Pietkiewicz and Smith, 2012) was used to evaluate data within these themes.

Mitra et al. included women with a wide range of physical disabilities, such as Achondroplasia, spinal muscular atrophy (SMA) and CP (Mitra et al., 2016). Interviews were analysed using an iterative, inter-

pretive process, resulting in three broad themes: 1) clinician knowledge and attitude, 2) physical accessibility of healthcare facilities and equipment, and 3) need for information related to pregnancy and postpartum support.

Smeltzer et al. included women with physical disabilities in the form of CP, SCI and ten other types of physical disabilities (Smeltzer et al., 2017). The interview guide covered eight broad top-

**Table 3**

Key themes and conclusions of individual studies.

Article	Key Themes	Key conclusion
Bertschy et al., 2015 Switzerland	<p>Women's perceived health needs</p> <p>Information about SCI and pregnancy;</p> <ol style="list-style-type: none"> <li>1 Specific health professionals' expertise;</li> <li>2 Medical treatment;</li> <li>3 Access to and availability of care facilities;</li> <li>4 Specific supplies and equipment;</li> <li>5 Improved integration of care.</li> </ol> <p>The health services used</p> <ol style="list-style-type: none"> <li>1 Involved health professionals;</li> <li>2 Consulted facilities;</li> <li>3 Perceived degree of services utilization</li> </ol>	<p>The existing health care services are far from being tailored to meet the needs and expectations of these mothers, and further improvements in both policy and practice are necessary to provide better health care to these women. Policy should provide a framework for health care providers that would allow them to most effectively meet the women's needs.</p>
Nguyen et al., 2020 Vietnam	<ol style="list-style-type: none"> <li>1 Technology and the search for "normal";</li> <li>2 "People with disabilities should not give birth";</li> <li>3 Information for "normal" women only;</li> <li>4 Increased direct and indirect costs;</li> <li>5 Confusing waiting and referral procedures;</li> <li>6 Poor accessibility of transportation, facilities, and equipment.</li> </ol>	<p>Although women with physical disabilities have the right to enjoy healthy motherhood and quality healthcare, the actions and inaction of many healthcare staff suggest otherwise. At present, many North Vietnamese healthcare services are ill-equipped to provide disability-inclusive and responsive maternal healthcare. Many challenges the women experienced are potential disincentives and limit the quality of care. The complex maternal healthcare needs of women with physical disabilities should be met by ensuring their genuine inclusion in mainstream healthcare services. The quality of perinatal care remains unsatisfactory and the resulting problems are not effectively resolved as they are often not even recognised. Health care professionals' training should be modified and their attitudes changed. Specific standards and procedures should be developed and introduced in clinical practice</p>
Mazurkiewicz et al., 2018) Poland	<ol style="list-style-type: none"> <li>1 Perceived stigma and lack of affirmation for the interviewee's motherhood;</li> <li>1 Accessibility of childbirth preparation;</li> <li>2 Accessibility of perinatal care and hospital facilities;</li> <li>3 Midwives' attitudes;</li> <li>4 Expectations for care improvements.</li> </ol>	<p>The quality of perinatal care remains unsatisfactory and the resulting problems are not effectively resolved as they are often not even recognised. Health care professionals' training should be modified and their attitudes changed. Specific standards and procedures should be developed and introduced in clinical practice</p>
Mitra et al., 2016) USA	<ol style="list-style-type: none"> <li>1 Clinician knowledge and attitudes;</li> <li>2 Physical accessibility of health care facilities and equipment;</li> <li>3 Need for information related to pregnancy and postpartum supports.</li> </ol>	<p>Clinicians should be provided with the education necessary to prepare them for the care of women with disabilities, and both formal and informal support should be made more widely available. There is a need for information about the potential impact of disability on pregnancy.</p>
Smeltzer et al., 2017 USA	<p>Labor and birth experience</p> <ol style="list-style-type: none"> <li>1 Women's preferences for type of delivery;</li> <li>2 Clinicians and some women expected no labor pain';</li> <li>3 Fears prompting active advocacy;</li> <li>4 Positive experiences.</li> </ol> <p>Obstetrical anaesthesia</p> <ol style="list-style-type: none"> <li>1 Importance of consultation with the anaesthesia team;</li> <li>2 Decisions about epidural/spinal vs general anaesthesia;</li> <li>3 Failed epidural with repeated efforts;</li> <li>4 Fear of injury related to anaesthesia.</li> </ol>	<p>Clinicians need to be educated and trained in order to provide more effective care, including knowledge and technical skills. Clinicians need greater attention to address the information needs of women with physical disabilities and their desire to be informed and consulted about treatment decisions. More effective communication with women about these issues is likely to increase their satisfaction with obstetric and anaesthesia care.</p>
Tarasoff, 2017 Canada	<ol style="list-style-type: none"> <li>1 Inaccessible care settings;</li> <li>2 Negative attitudes;</li> <li>3 Lack of knowledge and experience;</li> <li>4 Lack of communication and collaboration among providers;</li> <li>5 Misunderstandings of disability and disability-related needs.</li> </ol>	<p>Women with physical disabilities continue to encounter barriers, including inaccessible care settings and providers lacking disability knowledge. Providers need to do a better job of listening and working with these women. Collaboration among perinatal and disability-related providers and meaningful inclusion of women in educational initiatives and care plans are vital for improving care experiences.</p>
Ganle et al., 2016 Ghana	<p>Desire for children and experiences with pregnancy and childbirth</p> <p>Challenges to maternal healthcare access</p> <ol style="list-style-type: none"> <li>1 Mobility problems;</li> <li>2 Limited support;</li> <li>3 Communication problems;</li> <li>4 Unfriendly healthcare infrastructure;</li> <li>5 Healthcare providers' insensitivity and lack of knowledge.</li> </ol>	<p>Maternal healthcare services that are designed to address the needs of able-bodied women might lack the flexibility and responsiveness to meet the special maternity care needs of women with disability. More disability-related cultural competence and patient-centred training for healthcare providers as well as the provision of disability-friendly transport and healthcare facilities and services are needed.</p>

(continued on next page)

Table 3 (continued)

Article	Key Themes	Key conclusion
Smeltzer et al., 2016 USA	<ol style="list-style-type: none"> <li>1 Clinicians' lack of knowledge about pregnancy-related needs of women with physical disabilities;</li> <li>2 Clinicians' failure to consider women's knowledge, experience, and expertise about their own disabilities;</li> <li>3 Clinicians' lack of awareness of the reproductive concerns of women with physical disabilities.</li> </ol>	<p>Women's recommendations were based on their perceptions that health care clinicians lack knowledge about pregnancy within the context of disability and clinicians' failure to increase their knowledge to a level that inspires confidence in the women. The need on the part of clinicians to listen to women with physical disabilities and to respect them and their expertise and knowledge based on years of living with their disabilities was identified by almost all participants in the study.</p> <p>Further, women recommended that clinicians avoid stereotyping and bias and to view women with physical disabilities as sexual persons capable of becoming pregnant, having children, and becoming mothers. They expressed the need for clinicians to learn about and understand women's disabilities and to see women beyond their disabilities. Education of health care professionals about disability is essential to remove stigma and bias toward women with physical disabilities. Education of clinicians about the interaction of disability with pregnancy was identified as essential if women with physical disabilities are to receive the high-quality health care during pregnancy that they and their offspring deserve.</p>
Lipson and Rogers, 2000 USA	<p>Women's perspective</p> <ol style="list-style-type: none"> <li>1 The effect of the disability;</li> <li>2 Women's resources;</li> <li>3 Personality and approach.</li> </ol> <p>The health care system factors</p> <p>Pregnancy</p> <ol style="list-style-type: none"> <li>1 Health providers and parents' negative attitudes;</li> <li>2 Early referral, testing, and referral to occupational and physical therapy;</li> <li>3 Difficulties with usual prenatal care practices;</li> <li>4 Lack of information.</li> </ol> <p>Birth experiences</p> <ol style="list-style-type: none"> <li>1 Frequent use of high technology when women would have preferred to deliver vaginally if possible;</li> <li>2 Carefully made plans that did not work out;</li> <li>3 Insensitive hospital care.</li> </ol> <p>The postpartum period/infant care</p> <ol style="list-style-type: none"> <li>1 Insensitive care providers;</li> <li>2 Lack of referral to appropriate agencies;</li> <li>3 Lack of specialised instruction on lactation;</li> <li>4 Adaptive equipment;</li> <li>5 Help in learning techniques</li> </ol>	<p>The professional's positive attitude and support of a woman with a disability through recognizing and verbalizing that she has the ability to be involved in the care of her baby will bolster her confidence, which can impact the whole postpartum experience. We recommend training and values clarification for health care providers to help them provide more sensitive and appropriate care for women with disabilities. It is important for care providers to work as a team on behalf of women with disabilities. Health care providers should take responsibility for helping women assess their physical, social, and daily living needs so that they can obtain services to help them function to the best of their ability. Suggesting appropriate baby care equipment is important for all parents, but it is essential for parents with disabilities.</p>
Frederick, 2015 USA	Not reported	<p>Postnatal care is a particularly critical time when blind mothers are likely to face stigma in the form of discouragement and discrimination. When these mothers move from passive, labouring patients to the expected role of independent mothers, stigmatizing interactions are likely to occur. Participants expressed deep fear of the potential consequences of such stigmatizing interactions.</p>

ics related to pregnancy that can be divided into topics related to the experience of labour, birth and anaesthesia. These topics were used to structure the results.

Tarasoff primarily included women with physical disabilities such as arthritic conditions, CP and congenital amputation (Tarasoff, 2017). Some participants reported more than one impairment, and one participant reported a sensory disability in the form of congenital blindness. Analysis of the data was informed by a constructivist grounded theory approach, resulting in five interrelated themes regarding barriers to perinatal care.

Ganle et al. reported the experience of women with both physical and sensory disabilities in the form of speech, hearing and visual impairments (Ganle et al., 2016). The thematic network framework of Attride-Stirling (Attride-Stirling, 2001) was used to analyze the data, resulting in two categories and five themes related to the challenges of accessing maternal healthcare.

The mixed methods study of Smeltzer et al. included women with physical disabilities as CP, amputation, SMA and six other physical disabilities (Smeltzer et al., 2016). The semi-structured interview guide included 56 questions. The topics were related to women's perinatal experiences in general and their perceptions of the interaction of their disabilities and pregnancy. Analysis resulted in three themes relating to women's interactions with healthcare providers.

Lipson and Roger included women with physical disabilities such as CP, spina bifida and Achondroplasia (Lipson and Rogers, 2000). The resulting categories were divided into 'Women's perspective' and 'The healthcare system factors', in which a subdivision was made for periods of pregnancy, birth and postpartum.

#### Synthesis of results

Following data extraction, a total of 197 findings were imported into Microsoft Excel. A total of 61 findings were not used due to an 'unsupported' plausibility level. The remaining 49 equivocal and 87 unequivocal findings were used to form categories. The analysis of these findings resulted in thirteen categories and four synthesised findings.

Due to the inclusion of both physical and sensory disabilities, a distinction was made between disability type. Table 4 provides an overview of the synthesised findings and categories in combination with the disability type of the participants whose data were used to form categories.

#### Accessibility

The synthesised finding *Accessibility* includes the following categories: *facilities*, *equipment* and *educational programs*.



**Table 4**  
Synthesised findings and categories in combination with disabilities.

Synthesised findings	Categories	References
Accessibility	<b>Facilities</b> Physical	Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Nguyen et al., 2020 Tarasoff, 2017
	Physical (including one Visual) Sensory (Visual)	Mazurkiewicz et al., 2018
	Physical and Sensory (Speech, Hearing and Visual)	Ganle et al., 2016
	<b>Equipment</b> Physical	Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016 Tarasoff, 2017 Mazurkiewicz et al., 2018
Knowledge of healthcare providers	Physical (including one Visual) Sensory (Visual)	Bertschy et al., 2015 Mazurkiewicz et al., 2018
	<b>Lack of knowledge</b> Physical	Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2017, 2016 Tarasoff, 2017
	Physical (including one Visual) <b>Dismissal of women's concerns</b> Physical	Smeltzer et al., 2017 Tarasoff, 2017
	Physical (including one Visual) <b>Assistance</b> Sensory (Visual)	Mazurkiewicz et al., 2018 Ganle et al., 2016
Attitude of healthcare providers	Physical and Sensory (Speech, Hearing and Visual) <b>Communication</b> Sensory (Visual)	Mazurkiewicz et al., 2018 Ganle et al., 2016
	Speech and Hearing <b>Unwillingness to assist</b> Physical	Lipson and Rogers, 2000; Mitra et al., 2016; Nguyen et al., 2020 Tarasoff, 2017 Ganle et al., 2016
	Physical (including one Visual) Physical and Sensory (Speech, Hearing and Visual)	Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Smeltzer et al., 2017, 2016
	<b>Support</b> Physical	Nguyen et al., 2020; Smeltzer et al., 2016 Tarasoff, 2017 Ganle et al., 2016
Women's feelings	<b>Dehumanised</b> Physical	Bertschy et al., 2015; Smeltzer et al., 2017
	Physical (including one Visual) Physical and Sensory (Speech, Hearing and Visual)	Lipson and Rogers, 2000 Frederick, 2015
	<b>Afraid</b> Physical	Lipson and Rogers, 2000; Smeltzer et al., 2017
	<b>Vulnerable</b> Physical	Lipson and Rogers, 2000 Frederick, 2015
	<b>Advocate themselves</b> Physical	Lipson and Rogers, 2000; Smeltzer et al., 2017

*Facilities* refers to the spaces that women visit when accessing maternity care. There is strong evidence that women with physical and sensory disabilities experience barriers to accessing the maternity care facilities (Bertschy et al., 2015; Ganle et al., 2016; Lipson and Rogers, 2000; Mazurkiewicz et al., 2018; Mitra et al., 2016; Nguyen et al., 2020; Tarasoff, 2017). Women with physical disabilities report that rooms such as offices, restrooms and washrooms are inaccessible to wheelchairs (Bertschy et al., 2015; Ganle et al., 2016; Mitra et al., 2016; Nguyen et al., 2020; Tarasoff, 2017). One woman expressed pleasure at receiving a handicapped room – a larger room with adapted equipment in which she was able to use her walker and wheelchair (Lipson and Rogers, 2000). Women with sensory impairment express difficulties in finding their way around, especially if there is no one available to assist them (Ganle et al., 2016; Mazurkiewicz et al., 2018).

*Equipment* refers to a set of items used to assist women. There is strong evidence that there is limited access to adapted equipment for women with physical disabilities (Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Tarasoff, 2017). The examination

table, scales and baby equipment are commonly mentioned as not adapted to women's needs. There is insufficient evidence concerning equipment for women with sensory disabilities (Mazurkiewicz et al., 2018). One woman with visual impairment reported the following (Mazurkiewicz et al., 2018):

“During my stay in hospital all the facilities to support people with disabilities, making me feel safer and more comfortable, are important.” - OT

*Educational programs* refer to classes on preparation for childbirth. There is insufficient evidence that educational programs are not tailored to the needs of women with physical and sensory disabilities (Bertschy et al., 2015; Mazurkiewicz et al., 2018).

#### *Knowledge of healthcare providers*

The synthesised finding *Knowledge of healthcare providers* includes the following categories: *lack of knowledge*, *dismissal of women's concerns*, *assistance* and *communication*. Data related to women with sensory disabilities did not include findings in the categories *lack of knowledge* and

*dismissal of women's concerns.* In addition, data related to women with physical disabilities did not include findings on *communication*.

*Lack of knowledge* refers to limited information, facts and skills gained through education or experience. There is strong evidence that there is a lack of knowledge of the relationship between physical disability and pregnancy among healthcare providers (Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2016; Tarasoff, 2017; Tran et al., 2018). Furthermore, there is moderate evidence that women believe that caregivers do not seek relevant information (Bertschy et al., 2015; Lipson and Rogers, 2000). A woman with SCI reported the following (Bertschy et al., 2015):

“During my first appointment with the gynaecologist, I asked him if he had other patients like me before and if he knew the process. He told me: ‘No not at all.’ He said he could find out, but that he thought there was no problem. Then I said, ‘Yeah, but how am I going to give birth? And what will happen?’ I had a thousand questions besides all the standard questions of a standard pregnancy. Then he told me: ‘Well, we will see. I think you’re not a high-risk pregnancy. ‘He said:’ We’ll frame it as a normal pregnancy, and if you need monthly controls, we will do that, no problem.’ So, that was strange.” - Jeannine

*Dismissal of women's concerns* refers to the decision by a healthcare provider that something is not important or worth considering. There is strong evidence that healthcare providers dismiss the disability-related concerns of women with physical disabilities (Smeltzer et al., 2017; Tarasoff, 2017). Based on the experiences of women, healthcare providers appear to focus on one aspect of the disability and/or overlook women's disability-related concerns by focusing only on pregnancy and childbirth (Tarasoff, 2017).

*Assistance* refers to actions to help women with disabilities. There is insufficient evidence that women with physical disabilities experience long wait times for assistance from healthcare providers (Ganle et al., 2016). However, there is strong evidence that women with sensory disabilities believe that healthcare providers do not offer assistance unless explicitly requested (Ganle et al., 2016; Mazurkiewicz et al., 2018). Healthcare providers do not appear to recognise disabled women's needs.

*Communication* refers to information exchange by speaking, writing, or using another medium. There is insufficient evidence that women with sensory impairment encounter problems in communication with their healthcare providers (Ganle et al., 2016; Mazurkiewicz et al., 2018). However, women with visual impairment report that healthcare providers do not know how to demonstrate care (Mazurkiewicz et al., 2018). Verbal communication is insufficient for learning and communicating, as women with visual impairment experience familiarisation primarily through sense and touch (Mazurkiewicz et al., 2018). Women with speech and hearing impairments reported communication difficulties with healthcare providers unless they were accompanied by a partner (Ganle et al., 2016).

#### *Attitude of healthcare providers*

The synthesised finding *Attitude of healthcare providers* includes the following categories: *unwillingness to assist and support*. Data related to women with sensory disabilities did not include findings in either category.

*Unwillingness to assist* refers to the expression of unwillingness to help women with disability-related care. There is strong evidence that women with physical disabilities encounter unwillingness to provide assistance on the part of healthcare providers (Ganle et al., 2016; Lipson and Rogers, 2000; Mitra et al., 2016; Nguyen et al., 2020; Tarasoff, 2017). The women believe that healthcare providers are uncomfortable supporting disability-related needs (Ganle et al., 2016;

Tarasoff, 2017), and it is necessary for women's partners to help due to the providers' unwillingness to assist (Mitra et al., 2016; Tarasoff, 2017).

*Support* refers to the provision of encouragement or emotional assistance by healthcare providers. There is strong evidence that a supportive attitude from healthcare providers has a positive influence on the experiences of women with physical disabilities (Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Smeltzer et al., 2017, 2016). The women described healthcare providers who provided sensitive, respectful and supportive care (Bertschy et al., 2015; Lipson and Rogers, 2000; Mitra et al., 2016; Smeltzer et al., 2017, 2016), and one woman with CP reported the following (Smeltzer et al., 2017):

“[My obstetrician] knew...that I wasn't talking out of fear...that I had some knowledge and education to support my decisions. She really believed I knew my body the best and was willing to help me....She listened and she read my chart and she said “I see this is what you want ...you and your baby to come out of this healthy and fine.”...And she's like “you have every right...”

#### *Women's feelings*

The synthesised finding *Women's feelings* includes the following categories: *dehumanised, afraid, vulnerable and advocating for yourself*. Data related to women with sensory disabilities did not include findings in the categories *dehumanised, afraid* or *advocating for yourself*.

*Dehumanised* refers to feeling less than human. There is strong evidence that women with physical disabilities feel dehumanised through the actions of healthcare providers (Ganle et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2016; Tarasoff, 2017). These women described healthcare providers who shouted and made negative comments about their capacity for motherhood (Ganle et al., 2016; Nguyen et al., 2020; Smeltzer et al., 2016; Tarasoff, 2017). Women reported feeling like a spectacle (Tarasoff, 2017).

“They don't see me as a person anymore. I'm a disability. ... We were talking about something to do with my concerns, and she reached over and pulled my sleeve up. I tend to keep my sleeve down because I find it cuts down on my daily awkward exchanges and interactions. But she pulled my sleeve up and held my arms out to this resident. Like, “well you can see, she's got this disability and this disability.” And it made me feel like ok, so I'm not a person in this exchange. ... People didn't seem to pay much attention [to my disability]. When it did flip, it was the wrong kind of attention.”

*Afraid* refers to an unpleasant emotion caused by danger, pain or harm. There is strong evidence that women with physical disabilities fear anaesthetic injury (Bertschy et al., 2015; Smeltzer et al., 2017). They were afraid to re-experience moments of fear of functional limitations and reported fear of negative outcomes (Bertschy et al., 2015; Smeltzer et al., 2017).

*Vulnerable* refers to being easily hurt, influenced or attacked. There is insufficient evidence that women with physical and sensory disabilities feel vulnerable during the postpartum period (Frederick, 2015; Lipson and Rogers, 2000). Women experience the contradiction between being a dependent patient who must rely on the guidance of healthcare providers and being a disabled woman expected to demonstrate her capacity for independent motherhood (Frederick, 2015). In addition, when a presumption of incompetence leads to the involvement of social workers, women feel vulnerable and distressed (Frederick, 2015).

*Advocating for yourself* refers to advocating for one's needs. There is moderate evidence that women with physical disabilities experience a sense of advocacy for their needs (Lipson and Rogers, 2000; Smeltzer et al., 2017). The women viewed themselves as knowledgeable and sought information from different sources to communicate with healthcare providers (Smeltzer et al., 2017). In addition, the women chose to stay awake during childbirth and advocated for themselves

or sought advocacy from spouses in order to avoid poor outcomes (Smeltzer et al., 2017).

## Discussion

In this review, findings from ten studies were aggregated to provide an overview of the experiences of women with physical disabilities, including sensory disabilities, regarding maternity care. There is strong evidence that women with physical disabilities experience barriers related to accessibility of facilities, equipment, knowledge and healthcare providers' attitude towards their concerns, and unwillingness to assist. As a result, women feel dehumanised and afraid. However, support by healthcare providers has a positive influence on their experiences. In addition, women with sensory disabilities experience barriers to accessibility of facilities and a lack of assistance by healthcare providers.

With regard to the experiences of women with physical disabilities, little has changed in the last two decades; the barriers are consistent with studies conducted 20 years ago (Carty, 1998; Thomas and Curtis, 1997). These findings have also been confirmed by recent studies, including a review by Tarasoff that reports barriers to accessibility of facilities and equipment and care that is not tailored to women's needs (Iezzoni et al., 2015; Tarasoff, 2015; Walsh-Gallagher et al., 2012). Furthermore, healthcare providers who provide care to physically disabled women recognised the lack of accessible care facilities, equipment and disability-specific training as barriers (Mitra et al., 2017). Lack of knowledge leads healthcare providers to not feel competent in caring for physically disabled women (Walsh-Gallagher et al., 2013). The included studies reflect the notion that the pregnant body is assumed to be a non-disabled body, and this assumption establishes the practices and physical setting of maternity care. To improve accessibility to maternity care, it is recommended that spacious rooms, including adapted equipment, be provided. In addition, the findings of this review indicate a lack of knowledge among healthcare providers, which puts women with physical disabilities at risk of receiving inappropriate advice from well-intentioned providers, which can lead to difficulties making informed decisions. Improvement is only possible by raising awareness of the barriers faced by women with disabilities. Furthermore, the negative attitude of healthcare providers towards women with disabilities is problematic and appears to result from a lack of proper professional training (Guerin et al., 2017). Evidence-based knowledge and practice-based training for healthcare providers can ensure that all women's expectations are met (Smeltzer et al., 2018). We therefore recommend providing training sessions for healthcare providers to emphasise patient-centered care, teach effective collaboration with women and provide knowledge of the relationship between disabilities and pregnancy (Smeltzer et al., 2018). Because training involves several inter-related components and concerns behavioural changes in a number of healthcare provider groups, it is a complex intervention (Craig et al., 2008). Therefore, it is advisable to use the Medical Research Council (MRC) framework on complex interventions to guide the development and evaluation of training (Craig et al., 2008). The enriched development phase of the MRC framework can be used to improve the fit with clinical practice and the likelihood of success (Bleijenberg et al., 2018). Actively involving women with disabilities in the design and evaluation of the training is also recommended (Walsh-Gallagher et al., 2013).

Research should be conducted on how to best organise training to increase healthcare providers' knowledge. Furthermore, against a backdrop of heterogeneous studies, more comprehensive research is required to explore the experiences of women with sensory disabilities, including visual, speech and hearing impairments.

The strength of this systematic review is that various methodological methods have been used to increase reliability of the results. In addition, the search, data extraction and quality assessment were discussed until consensus was reached. Furthermore, by using the CASP, the limitations of individual studies were evaluated and the quality of each

study was taken into account in the synthesis. The use and description of these methods such as CASP (Critical Appraisal Skills Programme, 2018) and the meta-aggregation method (Lockwood et al., 2015) have also increased reproducibility. One study corresponding to Tarasoff's review was included in our review (Tarasoff, 2015). Other included studies in Tarasoff's review had no focus on maternity care, but on pregnancy in general. Consequently, these studies are not included in our review. Nine studies not included in the review of Tarasoff are included in our systematic review. Including the study of Nguyen et al. focusing on how access to maternal healthcare was experienced, this study reinforced all synthesised findings from our review (Nguyen et al., 2020).

However, this review also has several limitations. For example, the included studies mainly describe negative experiences. Therefore, the results may not provide an objective impression of women's experiences with maternity care. In addition, this review includes studies conducted in six countries in different contexts, which can potentially limit the generalizability of the findings. Additionally, one study that focused on physical disabilities but included one blind woman made no distinction in the findings; instead, all disabilities were classified as physical (Tarasoff, 2017). Limited data on women with sensory disabilities may be responsible for the rating of findings with moderate or insufficient evidence.

## Conclusion

This review demonstrates that women with physical disabilities continue to encounter several barriers in accessing maternity care related to inaccessible care settings, and lack of knowledge and negative attitude of healthcare providers. Care must be tailored to these women's needs and characteristics, and healthcare providers should be trained to be aware of the specific needs of women with physical and sensory disabilities. To this end, training should be developed and evaluated using the MRC framework.

## Declaration

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## Supplementary materials

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## References

- Ahumuza, S.E., Matovu, J.K.B., Ddamulira, J.B., Muhanguzi, F.K., 2014. Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda. *Reprod. Health* 11. doi:10.1186/1742-4755-11-59.
- Americans with disabilities act of 1990, as amended [WWW Document], 2008. URL <https://www.ada.gov/pubs/adastatute08.pdf> (accessed 3.25.19).
- Andersen, R.M., 1995. Revisiting the behavioral model and access to medical care: does it matter? *J. Health Soc. Behav.* 36, 1–10. doi:10.2307/2137284.
- Attride-Stirling, J., 2001. Thematic networks: An analytic tool for qualitative research. *Qual. Res.* 1, 385–405. doi:10.1177/146879410100100307.
- Bertschy, S., Geyh, S., Pannek, J., Meyer, T., 2015. Perceived needs and experiences with healthcare services of women with spinal cord injury during pregnancy and childbirth - A qualitative content analysis of focus groups and individual interviews. *BMC Health Serv. Res.* 15, 234. doi:10.1186/s12913-015-0878-0.
- Bleijenberg, N., de Man-van Ginkel, J.M., Trappenburg, J.C.A., Etema, R.G.A., Sino, C.G., Heim, N., Hafsteindóttir, T.B., Richards, D.A., Schuurmans, M.J., 2018. Increasing value and reducing waste by optimizing the development of complex interventions: Enriching the development phase of the Medical Research Council (MRC) Framework. *Int. J. Nurs. Stud.* 79, 86–93. doi:10.1016/j.ijnurstu.2017.12.001.
- Carty, E.M., 1998. Disability and childbirth: Meeting the challenges. *CMAJ* 159, 363–369.

- Clements, K.M., Mitra, M., Zhang, J., Iezzoni, L.I., 2016. Pregnancy characteristics and outcomes among women at risk for disability from health conditions identified in medical claims. *Women's Heal. Issues* 26, 504–510. doi:10.1016/j.whi.2016.06.001.
- Craig, P., Dieppe, P., Macintyre, S., Mitchie, S., Nazareth, I., Petticrew, M., 2008. Developing and evaluating complex interventions: The new Medical Research Council guidance. *Bmj* 337, 979–983. doi:10.1136/bmj.a1655.
- Critical Appraisal Skills Programme, 2018. CASP Qualitative Checklist. [WWW Document]. URL [https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018\\_fillable\\_form.pdf](https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf) (accessed 2.27.19).
- DomusVI, 2019. What are physical and intellectual disabilities? [WWW Document]. URL [www.domusvi.es/en/especialidad-medica/intellectual-and-physical-disabilities%0D](http://www.domusvi.es/en/especialidad-medica/intellectual-and-physical-disabilities%0D) (accessed 3.25.19).
- Frederick, A., 2015. Between stigma and mother-blame: blind mothers' experiences in USA hospital postnatal care. *Sociol. Health Illn.* 37, 1127–1141. doi:10.1111/1467-9566.12286.
- Ganle, J.K., Otupiri, E., Obeng, B., Edusie, A.K., Ankomah, A., Adanu, R., 2016. Challenges women with disability face in accessing and using maternal healthcare services in Ghana: A qualitative study. *PLoS One* 11. doi:10.1371/journal.pone.0158361.
- Government of Western Australia Department of communities Disability Services, 2015. What is disability? [WWW Document]. URL <http://www.disability.wa.gov.au/understanding-disability1/understanding-disability/what-is-disability/> (accessed 3.25.19).
- GPII DevelopersSpace, 2019. What is physical disability [WWW Document]. URL <https://ds.gpii.net/content/what-physical-disability%0D> (accessed 3.25.19).
- Guerin, B.M., Payne, D.A., Roy, D.E., McPherson, K.M., 2017. "It's just so bloody hard": recommendations for improving health interventions and maternity support services for disabled women. *Disabil. Rehabil.* 39, 2395–2403. doi:10.1080/09638288.2016.1226971.
- Hendriks, A., 2007. Convention on the rights of persons with disabilities (CRPD). *Eur. J. Health Law* 14, 273–298. doi:10.1163/092902707X240620.
- Iezzoni, L.I., Wint, A.J., Smeltzer, S.C., Ecker, J.L., 2015. Physical accessibility of routine prenatal care for women with mobility disability. *J. Women's Heal.* 24, 1006–1012. doi:10.1089/jwh.2015.5385.
- Iezzoni, L.I., Yu, J., Wint, A.J., Smeltzer, S.C., Ecker, J.L., 2013. Prevalence of current pregnancy among US women with and without chronic physical disabilities. *Med. Care* 51, 555–562. doi:10.1097/MLR.0b013e318290218d.
- Lipson, J.G., Rogers, J.G., 2000. Pregnancy, birth, and disability: Women's health care experiences. *Health Care Women Int* 21, 11–26. doi:10.1080/073993300245375.
- Lockwood, C., Munn, Z., Porritt, K., 2015. Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *Int. J. Evid. Based. Healthc.* 13, 179–187. doi:10.1097/XEB.0000000000000062.
- Mazurkiewicz, B., Stefaniak, M., Dmoch-Gajzlerska, E., 2018. Perinatal care needs and expectations of women with low vision or total blindness in Warsaw. *Poland. Disabil. Health J.* 11, 618–623. doi:10.1016/j.dhjo.2018.05.005.
- Mitra, M., Long-Bellil, L.M., Iezzoni, L.I., Smeltzer, S.C., Smith, L.D., 2016. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disabil. Health J.* 9, 457–463. doi:10.1016/j.dhjo.2015.12.007.
- Mitra, M., Smith, L.D., Smeltzer, S.C., Long-Bellil, L.M., Sammet Moring, N., Iezzoni, L.I., 2017. Barriers to providing maternity care to women with physical disabilities: Perspectives from health care practitioners. *Disabil. Health J.* 10, 445–450. doi:10.1016/j.dhjo.2016.12.021, <https://doi.org/https://doi.org/>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., Antes, G., Atkins, D., Barbour, V., Barrowman, N., Berlin, J.A., Clark, J., Clarke, M., Cook, D., D'Amico, R., Deeks, J.J., Devereaux, P.J., Dickersin, K., Egger, M., Ernst, E., Gøtzsche, P.C., Grimshaw, J., Guyatt, G., Higgins, J., Ioannidis, J.P.A., Kleijnen, J., Lang, T., Magrini, N., McNamee, D., Moja, L., Mulrow, C., Napoli, M., Oxman, A., Pham, B., Rennie, D., Sampson, M., Schulz, K.F., Shekelle, P.G., Tovey, D., Tugwell, P., 2009a. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *J. Chinese Integr. Med.* 7, 889–896. doi:10.1371/journal.pmed.1000097.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. The PRISMA Group, 2009b. PRISMA 2009 Flow Diagram. *PLoS Med* doi:10.1371/journal.pmed.1000097.
- Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., Costello, A., Groce, N., 2014. Disabled women's maternal and newborn health care in rural Nepal: A qualitative study. *Midwifery* 30, 1132–1139. doi:10.1016/j.midw.2014.03.012.
- Nguyen, T.V., King, J., Edwards, N., Dunne, M.P., 2020. Nothing suitable for us": experiences of women with physical disabilities in accessing maternal healthcare services in Northern Vietnam. *Disabil. Rehabil.* 1–9. doi:10.1080/09638288.2020.1773548.
- Ouzzani, M., Hammady, H., Fedorowicz, Z., Elmagarmid, A., 2016. Rayyan—a web and mobile app for systematic reviews. *Syst. Rev.* 5, 1–10. doi:10.1186/s13643-016-0384-4.
- Pietkiewicz, I., Smith, J.A., 2012. Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii [A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czas. Psychol. [Psychological Journal]* 18, 361–369. doi:10.14691/CPJP.20.1.7.
- Proper, K.I., Singh, A.S., Van Mechelen, W., Chinapaw, M.J.M., 2011. Sedentary behaviors and health outcomes among adults: A systematic review of prospective studies. *Am. J. Prev. Med.* 40, 174–182. doi:10.1016/j.amepre.2010.10.015.
- Roulstone, A., Barnes, C., 2005. Working futures?: Disabled people, policy and social inclusion. Policy Press, Bristol.
- Scheer, J., Kroll, T., Neri, M.T., Beatty, P., 2008. Access barriers for persons with disabilities: The consumer's perspective. *J. Disabil. Policy Stud.* 13, 221–230. doi:10.1177/104420730301300404.
- Schopp, L.H., Sanford, T.C., Hagglund, K.J., Gay, J.W., Coatney, M.A., 2002. Removing service barriers for women with physical disabilities: Promoting accessibility in the gynecologic care setting. *J. Midwifery Women's Heal.* 47, 74–79. doi:10.1016/S1526-9523(02)00216-7.
- Segen's Medical Dictionary, 2011. Maternity care [WWW Document]. URL <https://medical-dictionary.thefreedictionary.com/maternity+care> (accessed 2.13.19).
- Smeltzer, S.C., Mitra, M., Iezzoni, L.I., Long-Bellil, L., Smith, L.D., 2016. Perinatal Experiences of Women With Physical Disabilities and Their Recommendations for Clinicians. *J. Obstet. Gynecol. neonatal Nurs. JOGNN* 45, 781–789. doi:10.1016/j.jogn.2016.07.007.
- Smeltzer, S.C., Mitra, M., Long-Bellil, L., Iezzoni, L.I., Smith, L.D., 2018. Obstetric clinicians' experiences and educational preparation for caring for pregnant women with physical disabilities: A qualitative study. *Disabil. Health J.* 11, 8–13. doi:10.1016/j.dhjo.2017.07.004.
- Smeltzer, S.C., Wint, A.J., Ecker, J.L., Iezzoni, L.I., 2017. Labor, delivery, and anesthesia experiences of women with physical disability. *Birth* 44, 315–324. doi:10.1111/birt.12296.
- Tarasoff, L.A., 2017. "We don't know. We've never had anybody like you before": Barriers to perinatal care for women with physical disabilities. *Disabil. Health J.* 10, 426–433. doi:10.1016/j.dhjo.2017.03.017.
- Tarasoff, L.A., 2015. Experiences of women with physical disabilities during the perinatal period: a review of the literature and recommendations to improve care. *Health Care Women Int* 36, 88–107. doi:10.1080/07399332.2013.815756.
- Thomas, C., Curtis, P., 1997. Having a baby: some disabled women's reproductive experiences. *Midwifery* 13, 202–209. [https://doi.org/https://doi.org/10.1016/S0266-6138\(97\)80007-1](https://doi.org/https://doi.org/10.1016/S0266-6138(97)80007-1)
- Tran, H.T., Nippita, T., Nguyen, P.T.K., Nguyen, P.T.T., Huynh, T.T.D., Hua, O.T.Le, Roberts, C.L., 2018. Knowledge, experience and attitudes towards skin-to-skin contact following Caesarean sections among health professionals in Vietnam. *Acta Paediatr* 107, 1917–1923. doi:10.1111/apa.14519.
- Walsh-Gallagher, D., Mc Conkey, R., Sinclair, M., Clarke, R., 2013. Normalising birth for women with a disability: the challenges facing practitioners. *Midwifery* 29, 294–299. <https://doi.org/10.1016/j.midw.2011.10.007>
- Walsh-Gallagher, D., Sinclair, M., Mc Conkey, R., 2012. The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological understanding. *Midwifery* 28, 156–162. doi:10.1016/j.midw.2011.01.003.
- World Health Organization, 2018. Disability and health [WWW Document]. URL <https://www.who.int/en/news-room/fact-sheets/detail/disability-and-health> (accessed 3.25.19).
- World Health Organization, 2015. The prevention and elimination of disrespect and abuse during facility-based childbirth [WWW Document]. URL [https://apps.who.int/iris/bitstream/handle/10665/134588/WHO\\_RHR\\_14.23\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/134588/WHO_RHR_14.23_eng.pdf?sequence=1) (accessed 3.25.19).
- World Health Organization, 2011a. Disability. World report on disability. [WWW Document]. URL [https://www.who.int/disabilities/world\\_report/2011/report/en%0D](https://www.who.int/disabilities/world_report/2011/report/en%0D) (accessed 3.25.19).
- World Health Organization, 2011b. Health topics: Disabilities [WWW Document]. URL <https://www.who.int/topics/disabilities/en%0D> (accessed 3.25.19).
- World Health Organization, 2009. Promoting sexual and reproductive health for persons with disabilities. [WWW Document]. URL [https://apps.who.int/iris/bitstream/handle/10665/44207/9789241598682\\_eng.pdf;jsessionid=17FAB8ED29444A86D806449783DA3F07?sequence=1%0D](https://apps.who.int/iris/bitstream/handle/10665/44207/9789241598682_eng.pdf;jsessionid=17FAB8ED29444A86D806449783DA3F07?sequence=1%0D) (accessed 3.25.19).
- World Health Organization, 2005. The World health report: 2005: make every mother and child count. [WWW Document]. URL <https://apps.who.int/iris/bitstream/handle/10665/43131/9241562900.pdf?sequence=1%0D> (accessed 3.25.19).
- World Health Organization and World Bank, 2011. World report on disability 2011 [WWW Document]. URL [https://www.who.int/disabilities/world\\_report/2011/report.pdf?ua=1](https://www.who.int/disabilities/world_report/2011/report.pdf?ua=1) (accessed 3.25.19).